



2025 ANNUAL GENERAL MEETING

University of British Columbia - 2nd floor, Great Hall North, Vancouver, BC
Saturday, May 10, 2025 at 12:05 PM

MINUTES

1. Call to Order and Adoption of the Agenda

The Annual Meeting of the Garrod Association (*The Canadian Association of Centres for the Management of Hereditary Metabolic Diseases*) was called to order at 12:35pm.

Motion to approve the agenda of the 2025 Annual General meeting moved by Paula Waters, seconded by Jagdeep Walia – approved.

2. Motion to accept the 2024 meeting minutes

Motion to approve the minutes of the 2024 Annual General meeting moved by Cheryl Greenberg, seconded by Gabriella Horvath – approved.

3. President's Report – Aziz Mhanni

a. Executive committee: Gabriella Horvath has completed her one-year term as Symposium Officer. She is succeeded by Paula Waters, who will serve until the 2026 Joint Garrod – CCMG symposium. The Executive met monthly by Zoom, and had other frequent communications via email. Aziz Mhanni took the opportunity to thank Gabriella for her tireless and determined service for the past year and her leadership in chairing the 2025 Garrod Symposium. Aziz thanked all members of the Executive for their diligent and consistent work.

b. 2025 Symposium: Aziz expressed his deep appreciation to Gabriella Horvath (Chair) and all members of the local organizing committee in Vancouver, BC. He also thanked Darlene McCormack and her colleagues from McMaster CPD, for their invaluable contributions to the organization of the 2025 symposium.

c. Board of Directors: We currently have representatives (Directors) from all the 16 'Academic Treatment Centres' which form the core of the Garrod Association.

d. Committees and Working Group: There are several active committees and working groups. Aziz Mhanni thanked all Chairs, presenters of reports and group members for their contributions to the Association.

e. Garrod Association Website: Our Association Website has not been updated over the last two years. We lost access to modify the site content. We worked diligently to regain access to the website but this has not been possible. We now have started on a fresh initiative to construct a new website. We



will keep you all informed once the new website is up and running. A chat forum for communication among members will be added to the website.

f. Communications: A periodic Newsletter is sent to all members to keep all informed. Members are encouraged to update the Garrod Association with any ideas for the newsletter.

g. Membership: We now have nearly 320 members. This reflects a continuing active drive to build up our membership, particularly to encourage trainees and allied health professionals (who are eligible to be Regular Members) to join. The annual membership fee has still been kept very low, at \$30. The symposium registration fee structure is set up to provide an incentive, i.e. cheaper registration fees for all members versus those for non-members.

h. Administrative Assistance: We have recently signed a contract with a new management firm (Events & Management Plus (EM+)) to provide the Garrod Association with ongoing administrative support including the organization of the Annual Symposia.

i. Liaisons between Garrod Association and other societies:

- 1) Society for the Study of Inborn Errors of Metabolism (SSIEM) – our representative is Grant Mitchell.
- 2) Society for Inherited Metabolic Disorders (SIMD) – our representative is David Sinasac.

j. Future symposia and conferences:

- 1) The 2026 Garrod Symposium will be organized as a joint event together with the Canadian College of Medical Geneticists. The symposium will be held in Bromont, Québec, with Paula Waters leading the local organizing committee and serving as a liaison between the Garrod Association and the CCMG.
- 2) The 2027 Symposium will take place in Halifax, NS.
- 3) The 2028 Symposium will take place in Saskatoon, SK.
- 4) It has been confirmed that the 2029 ICIEM (International Congress of Inborn Errors of Metabolism) will be held in Toronto. The Garrod Association and SIMD together submitted a joint bid to the ICIEM International Organizing Committee, which was successful. Congratulations go to Andreas Schulze, who is leading this initiative.

4. Finance report – Nathalie Lepage

Copy of slides archived, available on request.

Nathalie Lepage thanked Jagdeep Walia, Past Treasurer, for a great transition.

- As of March 31, 2025, the association has a balance of \$196,697.27.



5. Auditors

Copy of the Financial Audit Statement archived, available on request.

The 2025 Finance report was audited by Pierre Allard and Lauren MacNeil, two Garrod members. Pierre Allard and Lauren MacNeil confirmed that the numbers were correct and they were satisfied that there were no omissions or other concerns. They completed a Financial Audit Statement on May 5, 2025.

6. Liaison and Relationships Committee report – Cheryl Greenberg

Members: Dr. Saadet Andrews, Dr. John Mitchell, Dr. Sandra Sirrs, Dr. Andreas Schulze, Dr. Sarah Dyack, Dr. Cheryl Rockman-Greenberg (Chair)

There were no significant activities brought to the attention of the Legislation and Regulation Committee over the past year, with the exception of one recent initiative. A representative from the L&R Committee was invited to attend a meeting requested by CanPKU with the Food and Drug Directorate of Health Canada, scheduled for May 2, 2025. The purpose of the meeting is to discuss the potential impacts of U.S. tariffs and trade measures, as well as Canadian countermeasures, on patient access to medical foods, medical formulas, and medically necessary supplements. Outcomes of this meeting will be shared with members once available.

Cheryl Rockman-Greenberg was unable to attend the Health Canada meeting, however, John Mitchell attended on behalf of the group. It was noted that Health Canada has indicated they will monitor potential tariff-related issues and communicate if concerns arise. Discussions are ongoing, and further information will be shared as it becomes available.

Additional updates were provided regarding ongoing engagement with physician advisory and industry advisory groups. While these groups remain committed to providing input, progress has been slow, and there has been limited movement on key issues. Members expressed ongoing frustration with the pace of work, despite continued efforts to provide advice related to drug funding and metabolic products. It was noted that there are opportunities for provincial funding to support metabolic care networks, and that dedicated funding would be beneficial if made available.

7. Guideline Committee report – Andrea Yu

Members: Daniela Buhas, MD – McGill; Pranesh Chakraborty, MD – CHEO; Sarah Dyack, MD – IWK Health Centre; Michal Inbar Feigenberg, MD – Sick Kids; Shaily Jain, MD – Edmonton; Graeme Nimmo, MD – UHN; Beth Potter, PhD – Ottawa; Murray Potter, MD – Hamilton; Ingrid Tein, MD – Sick Kids; Andrea C Yu, MD – CHEO (Chair)

Improving Communications

- Feedback from the previous AGM highlighted challenges with the former Garrod website, including limitations in layout and accessibility, which created barriers to disseminating the committee's work.
- The committee reviewed the feedback received and identified multiple areas for improvement, with a particular focus on communication and member engagement.



- Improving the functionality and format of the new Garrod website was identified as a priority.
- Proposed enhancements include:
 - Presenting endorsed guidelines in a clearer and more accessible format.
 - Adding functionality to allow Garrod members to provide feedback and comments on committee work.
 - Ensuring that any feedback mechanism is restricted to members only, to prevent non-member or automated input.
- Explore further collaboration with CCMG for publication, since trainees are more likely to consult CCMG website than the Garrod website.

ER Letters Template Project

- Emergency Room letter templates were received from nine centres across Canada.
- The submitted information is currently being collated and tabulated by a research coordinator based in Kingston in preparation for review by Garrod Guidelines Committee.
- Two fellows have agreed to assist with the collation process.
- The next step will involve compiling the information into a draft document for review.
- The draft will then be discussed by the Guidelines Committee to identify common elements and areas of standardization.

Industry Grants to Support Guideline Development

- The committee discussed the resource-intensive nature of guideline development and the need for Canadian-specific clinical guidelines.
- It was noted that industry partners have expressed willingness to provide grants or sponsorship for guideline development.
- The committee identified the need to minimize both real and perceived conflicts of interest.
- A previous request for Garrod review and endorsement of a guideline document raised concerns regarding the role of industry in its development and the process by which recommendations were created.
- Members emphasized that guideline content should be developed independently of industry influence.
- Discussion highlighted the current lack of infrastructure and administrative support for guideline development, including limitations in time and resources.
- Suggestions included:
 - Establishing a clear framework outlining requirements for guideline submission, review, and endorsement by the Garrod Association.
 - Creating a structured review process whereby guidelines are assessed by a committee before being presented to the membership for consideration.
- Members agreed on the importance of maintaining academic independence and avoiding industry involvement in guideline content.
- Conclusion: For the time being, guideline development and endorsement will remain academic in nature, without industry collaboration. Alternative endorsement pathways, such as through academic institutions or universities, may be pursued. The committee will continue working



toward developing appropriate policies and infrastructure to support guideline development in the future.

8. Award Program report – Aziz Mhanni

Members: Dr. Sarah Dyack, Dr. Anna Lehman, Dr. Grant Mitchell, Dr. Tony Rupar, Dr. Neal Sondheimer, Dr. Aziz Mhanni (Chair)

a) Garrod Trainee Research Award:

- i. Award program approved in 2021 and implemented in 2022. Three research awards are available per year, \$10,000 each.
- ii. A research award review committee was formed (Tony Rupar; Grant Mitchell; Sarah Dyack; Neal Sondheimer; Anna Lehman; Aziz Mhanni).
- iii. The guidelines and application form, and deadline for the application is posted on the website. However, this has been problematic due to our inability to access the website to update the documents and announcements.
- iv. Trainee Research Awards (2024): Two applicants for the research award 2024 – neither qualified based on current application criteria. No research awards advanced in 2024
- v. Trainee Research Awards (2025):
The Research Awards deadline for 2025: October 28th, 2025, 23:00 Central Time.

b) Garrod Trainee Educational Award:

- i. Award program to support trainees attending educational courses, approved in 2023 and implemented in 2023.
- ii. Four awards available per year, \$1000 each.
- iii. Guidelines were circulated via e-mail, and will also “be posted on the Website” when feasible.
- iv. Deadlines for Submission are 4:00 pm on March 8th and September 15th each year.
- v. 2025: There were 6 applications received. Five applications were eligible and were granted the award. The sixth application was not eligible and was declined.

c) Garrod Trainee Travel Award:

- i. The possibility of creating a third award program - to support trainees attending conferences - has been raised in the past. This proposal remains on our radar to consider and work on.

9. Royal College subspecialty training, working group report – Sandra Sirrs

Members: Dr. Danielle Bourque, Dr. Marisa Chard, Dr. Shailly Jain, Dr. Hugh McMillan, Dr. John Mitchell, Dr. Trudy Nasmyth, , , Dr. Hanna Faghfoury (Chair), Dr. Sandra Sirrs (Vice-Chair)

Updates

- The Royal College approved the creation of a subspecialty in Inherited Metabolic Diseases Medicine (IMD Medicine) on July 3 2024.



- This subspecialty will have two streams (adult and pediatric) and multiple routes of entry (Medical Genetics, Internal Medicine, Pediatrics, adult/pediatric Neurology)
- The Royal College will convene a committee chaired by Dr. Hanna Faghfouri to develop standards of accreditation. The first meeting of this committee will be in the second quarter of 2025 and this process is expected to take 2 years
- Program directors from the current CCMG accredited programs have been invited to participate in an information session with Hanna Faghfouri, Danielle Bourque, and Sandra Sirrs April 8 2025 to discuss work that can be done in the interval while standards are being developed.

The working group continues to advance the creation of a new subspecialty in Inherited Metabolic Disorders (IMD) medicine, aiming to increase visibility and provide multiple routes of entry for trainees. While initial submissions were previously rejected, the project has now been formally approved, and a dedicated working group of seven members has been tasked with developing the program. Discussions with CCMG representatives highlighted areas of work that can be undertaken immediately while formal accreditation standards are being developed.

The Garrod Association sees significant value in this project and is happy to provide administrative support, including help with communications between groups.

Questions regarding program location were addressed, noting that not all subspecialties are based in universities and that accreditation requires significant effort. The working group will initially focus on existing CCMG sites to avoid duplicating efforts and to streamline program development. The project also includes important considerations such as physician funding, which will be addressed in parallel over the three-year development timeline. Members emphasized the value of national expertise for trainee education, rather than limiting training to local resources.

There was also discussion about enhancing the public visibility of the subspecialty within the Garrod Association and shaping subgroups within the membership to reflect the evolving program.

The group expressed gratitude to Hanna Faghfouri and the working group for their leadership and efforts in advancing this historic initiative.

10. Varia

There were no additional items discussed during the meeting

11. Conclusion

The meeting was adjourned at 1:40pm.